Witness Name: GRO-B
Statement No.: WITN0424001
Exhibits: WITN0424002
Dated: 3|2|2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 September 2019.

I, GRO-B, will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1966 and my address is known to the Inquiry. My first husband GRO-B: H was a Haemophiliac who was infected with Human Immunodeficiency Virus (HIV). H was born on GRO-B 1959 and died on GRO-B 1988. My husband infected me with HIV.

2. I intend to speak about my husband H my two children and myself. In particular, the nature of our illness, how the illness affected us, the treatment received and the impact it had on our lives together.

Section 2. How Infected

3. My husband, H and I met at the beginning of 1984. He was older than me. We met at a bar. I was getting followed by a neighbour at the time so I was a bit nervous. H offered to walk me home and then things progressed from there. I was only 18 years old at the time.

4. H didn't have much of a career. He worked in GRO-B GRO-B For school, I think H went to a special needs school in the South of England called Treloar's College.

5. I went to the school to visit the teachers with H H loved the school and wanted to see the staff and pupils again. Some of the children had Christmas Disease and others had Haemophilia.

6. Since being in contact with the Infected Blood Inquiry, they have received documents regarding H The Inquiry has informed me that H attended Treloar's College when he was a teenager.

7. I knew he was a Haemophiliac. But I didn't know what it was.

8. In October 1984, he came to my work and picked me up. He said 'I think we need to call it a day. There is a lot going on and we need to call it off.'

9. He was in a rush to get to a meeting. He kept saying 'I need to go to a meeting'. H felt like we couldn't be together. He didn't properly explain himself but in hindsight, I think it was the fear he had about having HIV. I didn't know what the meeting was about. But it may have been a meeting for those who have Haemophilia who were also infected with HIV. Despite the fight, we stayed together.

10. A couple months later, he picked us up from work one lunchtime. I had taken a pregnancy test at home and needed to go to hospital to have it confirmed. We also went to the hospital as H had blood tests results waiting for him. H often had bloods taken. He didn't explicitly tell me that he was awaiting important test results. I didn't know that it was a test for HIV.

11. When we went to the hospital we found out he was HIV positive and they confirmed I was pregnant.

12. After the shock of H being HIV positive, I asked the nurse, 'Do I need a blood test?'. But apparently, they had already taken a blood test without my knowledge and I found out I was HIV positive, as well.

13. This was a difficult time for my family. My dad was a GRO-B and back then you had to be married. He was a very well-respected man. A daughter unmarried and pregnant was very painful for my parents. They told me to either get married or get an abortion. They didn't know about the HIV at this point.

14. H was older than me, so we decided to have the child. We wanted to give it a chance. The medical staff said that 'we strongly recommend you have an abortion. The child will not last 3 months.'

15. I had my appendix out when I was 5 months pregnant. I felt like a leper. The medical staff treated me like I was going to the moon. The way they were dressed, and the fact that the equipment and theatre room were covered in cling film made me feel so uncomfortable.

16. My son was born in GRO-B 1985. His name is also GRO-B: S but we call him S. During my delivery, the medical staff made me feel like I was going to the moon. I had a caesarean as I had high blood pressure. S came a week early from my due date. The staff told me that the theatre was kept ready just for me. Everything there was covered in cling film. Everything! They set up the isolation room and the theatre for me in Newcastle General Hospital. The staff were dressed in visors and goggles in the isolation ward. The Hospital has since been knocked down.

17. Dr Peter Jones was my doctor for about 2 years in the Newcastle Haemophilia Centre based at the Royal Victoria Infirmary. He was a very good doctor, he was supportive and loved his patients. H was a patient of Dr Peter Jones for years and years, since he was young. They had a very good relationship too. Anything we needed, Dr Peter Jones was there for us.

18. When I had S, my parents were not present at the birth. At this stage my parents still didn't know about my HIV. Dr Peter Jones told me that 'you need to tell your parents'. I was forced to tell my parents a few days after the birth. Dr Peter Jones said that 'if they are changing the baby's nappy and they could get infected. They deserve to know'.

19. I had to treat the nappies like clinical waste. I would throw them in a black bag and then bring them to a tip. I am mentally scarred from this whole ordeal.

20. My husband H was very ill, and was back and forth from the hospital. I went to HIV meetings every week. We had weekly check-ups with the baby and me getting blood tests all the time.

21. I used to give H Factor VIII in the house. He was a severe Haemophiliac. He started on Cryoprecipitate but mainly received Factor VIII. We would have a bleed every other week. So, between H and S we would spend a lot of time at the hospital.

22. We had several doctors for S, Dr Snow (Tropical Disease Department in the General Hospital) was one of them. He terrified us. We walked into his office and the first thing he said to us was, 'have you planned your funeral? We do not know how long you will live.' It was a constant reminder. They would tell me that 'if you breastfeed, your baby will die'. The smallest things became so complicated.

23. I had started missing appointments. But then I got transferred to Dr Ong and he was amazing. If it wasn't for him then I wouldn't have turned up to the hospital. I was frightened that I wouldn't see the next week.

24. For blood tests, S had to get blood taken from his head, as his veins were so small. He was born HIV positive but his immune system developed. After about 15 months his body was able to clear the virus. He was then a healthy baby.

25. I thought to myself that I could have ended his life, before I even had him.

26. One day (1986-88), I had a call from Dr Peter Jones. 'There has been a leak.' He called me and H and said, 'the press could be outside your door. Do not answer the door. Just call the centre. We are not 100% sure if your name is on it'. All we knew was that somebody may have said something to the press or that someone had got data and information about those infected with HIV. I had a new baby and this was very worrying.

Hs Treatment

27. My husband H didn't know how long he had been HIV positive for. They just knew from his test results that his blood tests were poor.

28. We didn't know how H got infected. The medical staff didn't talk about batch numbers or anything like that. H had two tattoos but he got them done in the UK. He presumably got infected from the Factor VIII.

29. He went on to treatment straight away.

30. From then, everything was just crap. The hospital put H on Azidothymidine (AZT) medication and it didn't do well for him. He started getting side effects and remained on the treatment until he died.

31. We moved closer to Hs sister's house when S was 5 months old as he started to get poorly.

32. We thought he was getting worse because of the medication. But then he got tests done and he had full blown Acquired Immune Deficiency Syndrome (AIDS). This was around 1987/88.

33. I was told that if you have AIDS you only have 2 years to live. I always hoped it would never get to that.

34. One day in 1988, he just started crying when we were sitting down. He said to me 'I am not well'. Then after this conversation, about 5-6 weeks he got gravely ill.

35. H had Crohn's disease as well. This got worse towards the end, but it was the Haemophilia that was the main bother.

36. On GRO-B 1988, he went in for tests and was supposed to be coming out of hospital. His breathing had become really bad. The staff told me to call his parents to come to the hospital. I spent all weekend with him. I wanted him to hang on until Tuesday.

37. On Tuesday the Haemophilia Centre would open. I just wanted him to hang on until then, but he didn't. He had been looked after by the Haemophilia Centre all his life.

38. H died on GRO-B 1988. He died in the Royal Victoria Infirmary, Ward 13. S was not even 3 years old at this stage. On his death certificate it reads that causes of death was pneumonia and Haemophila. This exhibit is labelled **WITN0424002.**

My Treatment

39. I was only with H for 8 months and I was in good health. So, they didn't offer me any medication when I found out I had HIV. Later on, in the years, they did offer me medication but I declined the treatment.

40. I only started taking medication about 15 years ago. My hospital visits and tests got extended from every month to every 3 months. Around the years 2000-02, Dr Ong said that the time was right to start for me to start treatment. I'm not aware if my bloods had got worse but he asked me if I would start treatment and I agreed.

41. I took Combivir which was a two-tablet combination drug. I took them three times a day. About 5 months later I changed to just one tablet (Combivir). But my skin started getting very thin and my body got used to the drug as I was on it for 10 years. So I changed to Descovy medicine (200/25mg) which I currently take.

Post H s death

42. Around 6-7 months after H s death I met my second husband. I fell pregnant, but I aborted my first pregnancy with him. I didn't realise but he was just looking for my money. After H s death, we got a pay-out from the High Court.

43. He was quite abusive. He used to say to me 'nobody will want you'. My mum caught him hitting me and she nearly killed him. All I wanted was to grow old with someone.

44. In 1992, my second child GRO-B: D was born. She too was born one week early and was HIV positive. They still used cling film around the machines in the hospital theatre but I felt a bit more comfortable. I had a proper midwife and she wasn't dressed like she was going to the moon. My daughter passed the virus like S did, through their immune system.

45. My second husband and I ended up divorcing.

46. My third and current husband is named GRO-B We have been happily married for 10 years and he is a GRO-B . We do lots of running and walking together with our beautiful dog. I need to keep training and exercising to stay strong.

Section 3. Other Infections

47. H didn't talk much about having other infections like Hepatitis. But there may have been a mention of Hepatitis. If he did have it, he didn't pass it on to me.

Section 4. Consent

48. H got told he was infected when he was with me. Within my knowledge H had not been tested, without his consent.

49. The medical staff tested my blood for HIV without my knowledge and consent.

Section 5. Impact

Physical and Mental Impact

50. I have been through a lot. The loneliness has been all consuming, and listening to people on the street talking about HIV can be so difficult. I have been so sad about it.

51. In the early days, having HIV made you feel so dirty. They would wash your cups with steriliser. I still feel there is a stigma. I still feel dirty.

52. My life seemed to be loads of lies. People would ask me where S was born and I would say the General Hospital, but everyone had children in St Mary's Hospital for children. I would start stuttering. The simplest things were hard to keep up with.

53. H looked anorexic. He looked like a skeleton at the end of this life. He was so skinny. But this affected me too. I would stand in front of the mirror, sucking in my cheekbones and sucking in my stomach every morning. I would imagine what I would look like. It was so hard. I didn't know when I would die.

54. One year I went to a dentist. I had to fill out a form and the form asked if I had HIV. I ticked the 'No' box and gave in the forms. But then I got so worked up, I told the receptionist what I had done and to return the forms to me. The dentist took me into an office and said 'you need to go to the hospital and get your teeth done there.' I was only 20 odd, and everything was just so difficult.

55. I started smoking as the doctors were telling me it wouldn't make much of a difference. During this ordeal, I didn't confide in many people. Then one day I told a friend about what was going on. But she told her best friend, as soon as I left her house. I just felt so let down, as I had hardly told anyone.

56. My friend did help me to stop smoking. I always wanted to be a Personal Trainer in the army, she got me going to the gym again. I started bodybuilding and went to the gym 5-6 times a week. She also tried to help me get a mortgage, with assistance from the Haemophilia Centre.

57. It was such a difficult time looking after S and H S S would sometimes go to a nursery. If I had a full day at the hospital and H had a bad bleed, S would go to nursery. But it turns out that the children were abused at the nursery. I made a complaint that I found my child crying in a room alone. I came to pick him up and he was just crying in a room on his own. It was all too much.

58. I recall when S needed vaccinations and the GPs came to my house to give a 'dead vaccination' to him. The GPs would come in twos, it felt like they wanted a 'show'. The 2 GPs came to my house and said 'if I give him a live injection then he will die'. They shouldn't have spoken to me like this. I was so frightened for years.

59. I only told my son 4 years ago about the HIV. I tried to protect my children. My son is soft, he is just like his father. I only told D my daughter about 3 years ago. She kept asking questions about H s death. I originally only told them that H died of blood Cancer and Haemophilia.

60. I personally associated HIV with gay men and drug users. This caused issues in my household. When my son was 17 years old he came out as gay. I found this difficult. GRO-C GRO-C

Physical and Mental Impact on H

61. H wanted to spend as much time with S as possible. He didn't want to leave. He was frightened and there was a lot of crying of what was to come. He was not working at this point. It was the infection that caused him to stop working.

62. He hurt all over his body in 1988. He also had a fever and flu like symptoms a lot, and was lethargic and tired. It was hard to tell if it was the HIV or side effects of the medication. Every week there was something wrong.

63. I don't think H would have gone to University, so his illnesses didn't hurt him educationally. However, he did give up his work. He became immobile, and couldn't get around. I had S to look after as well so we are on benefits to survive.

Section 6. Treatment/Care/Support

64. H never had counselling.

65. I was in the hospital getting a check-up, about 10 years after H s death and a nurse said to me 'you know you haven't grieved, I think you need to see a counsellor'. I had counselling in the General Hospital and I was put on antidepressants.

Section 7. Financial Assistance

66. In the early 1990s, the High Court paid out money to myself and S S We must have gone to a solicitor as part of a Haemophiliac group action when H was alive. So when he died I got around £20k and S got £20k, to pay out when he was 18.

67. I also got money through the Macfarlane Trust via the Skipton Fund. I started getting money about 10 years ago. I receive quarterly payments and I get monthly payments.

Section 8. Other Issues

68. The current financial assistance doesn't give us an incentive to work because if I work (I'm self-employed) and have a good financial year, then I get less money from the fund. It is hard for us, as we want to work hard and do well. I do work for the GRO-B charity for redecorating and refurbishment.

69. England Infected Blood Support Scheme (EIBSS) once over paid me £200 and I called them up to tell them. They said 'don't worry you don't have to give the money back'. They know each month what I earn and therefore what I am owed by them.

70. The scheme take into consideration my husband's income as well. It is means tested. I work really hard and other people are not working and they have the same money coming in. They are not paying for prescriptions. I feel bitter. My husband has had a back operation and hasn't been working as much. Sometimes we get £250-£400 a month. It changes each month.

I have given some other papers that I have to the Inquiry Investigators these are listed here:

Exhibit number	Date	Comment
WITN0424002	GRO-B 1988	Death Certificate for H H Cites cause of death: - Pneumocystis Pneumonia - Haemophilia A

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-B

Dated 3/2/2020